Chapter 2

Surveillance

South Carolina Cancer Prevention and Control

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The South Carolina Central Cancer Registry (SCCCR) is a population-based system for the collection, storage, analysis, and interpretation of data on South Carolinians with cancer.

It is located in the SC Department of Health and Environmental Control (DHEC), Office of Public Health Statistics and Information Systems (PHSIS). The SCCCR works cooperatively with DHEC Cancer Prevention and Control. Planning began for the registry in September, 1994, with a grant from the Centers for Disease Control and the registry began its full operation on January 1, 1996.

The central registry collects information on new cases of cancer in the state. For every new case of cancer, the registry records:

- When the cancer was diagnosed.
- Where the cancer occurred in the body.
- How far advanced the cancer was when it was found.
- Cancer type.
- The patient's treatment.
- Basic information like name, address, age, race, gender and county of residence.

Data will be used to determine the number, types, and severity of new cancer cases diagnosed each year in the state; to study trends on how often cancers occur in a defined area; to identify high risk groups that need to be targeted for cancer education, prevention, and screening; to provide information necessary to answer public questions about cancer in the community; to investigate the possible occurrence of more cancer cases than normal in a geographic area; and to provide information for scientific and medical research about cancer in the state.

Basic information comes from patients' medical records. All names and all data that could identify a patient are kept strictly confidential.

Registry Process

A mechanism for collection of cancer data is now established in all South Carolina acute-care hospitals, either through the individual hospital cancer program or through affiliation with a regional cancer registry operating in the state. These hospitals are categorized as: 1) hospitals with cancer registries, 2) hospitals reporting to regional cancer registries, 3) hospitals which neither have a cancer registry nor report to a regional cancer registry.

There are 22 hospital-based cancer registries staffed by trained cancer registrars. These hospitals are tertiary care centers providing treatment for patients referred from local facilities. Four of these hospitals report cancer data via a regional cancer registry. These hospitals are visited by a "circuit-riding" abstractor periodically. These hospitals have signed voluntary agreements with DHEC to allow the respective regional registry to report hospital data to the SCCCR. This policy avoids duplication of reporting. Thirty-seven hospitals do not have cancer registries and are not served by a regional registry. The SCCCR field abstractor monitors cancer cases at these facilities. No cost is incurred by the hospital for this service.

Coordination with State Agencies

Before the SCCCR was established, the only cancer morbidity data available in South Carolina was from the SC Budget and Control Board, Office of Research and Statistical Services (ORSS) which records all state hospital discharges by specific diagnosis. SCCCR continues to use statistical information from ORSS, and also cooperates with the Governor's Data Oversight Council. The SCCCR will also coordinate with the Geographic Information Systems group within DHEC to monitor geographic variation of cancer occurrences across the state.

Coordination with Non-Hospital Data Sources

In compliance with standards established by the American College of Surgeons and the North American Association of Central Cancer Registries (NAACCR) Council, information is collected from non-hospital sources. Because many cancer patients are diagnosed and treated in ambulatory care settings, the registry has initiated procedures to collect cancer patient data from both pathology laboratories and physicians' offices.

Benefits of SCCCR Data Collection and Analysis

The SCCCR allows DHEC to finally achieve long-standing objectives. An overall evaluation of the timeliness of patient diagnosis and efficacy of cancer treatment will emerge from analysis of the SCCCR database. Since data collection is conducted according to the guidelines of the National Program of Cancer Registries standards, the SCCCR data will be readily incorporated into national cancer surveillance efforts.

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance Survey (BRFSS) is another key surveillance group within DHEC. BRFSS is coordinated by the Centers for Disease Control (CDC), and collects information about lifestyle choices and screening practices. This information is critical to the fight against cancer because a large percentage of cancers are associated with personal health behaviors. Over half of all annual cancer deaths in the US are attributable to behavior: one third to tobacco use and another third to unhealthy diets. BRFSS monitors such behaviors as:

- Tobacco and alcohol use.
- Dietary patterns.
- Physical inactivity.
- Use of preventive health services, such as breast and cervical cancer screening.
- Access to health care.

BRFSS interviewers contact adults 18 and older in a periodic telephone survey. Participants are selected through a random digit dialing method, so all South Carolinians with telephones are eligible. Data are then forwarded to CDC for weighting.

A separate survey, the Youth Risk Behavior Survey (YRBS), is conducted among high school students between grades 9 and 12. Questions in the YRBS survey include behaviors which result in the greatest premature morbidity, mortality, and social problems among youth, including: tobacco use, alcohol and other drug use, sexual behaviors that could result in HIV infection, unintended pregnancies, and dietary excesses and imbalances.

Because the BRFSS and YRBS surveys are conducted in every state, they allow researchers

and public health planners to compare South Carolina with the rest of the nation. These surveys help researchers compare differences within the state as well: between men and women, blacks and whites, different age groups, and people with different income and education levels. This information helps determine which public health problems warrant the most attention and also helps DHEC tailor health education programs toward those who most need them.

Cancer and the Environment

Cancer Cluster Investigations

Rachel Mayo, Dr PH, Clemson University

DHEC maintains a Cancer Cluster Hotline to respond to citizens' concerns about cancer in their communities. When citizens call the SC Cancer Cluster Hotline, investigators gather information about individuals with cancer in that community, as well as provide cancer education and resources to help the caller learn more about cancer.

A "cancer cluster" is a group of more cancer cases than normal in a small area, like a neighborhood, or within a short period of time. People report suspected cancer clusters to DHEC when they believe that an unusual number of their friends, family, neighbors or co-workers have cancer, even though cancer is very common.

A "true cancer cluster" is a very rare event, and exists when several cases of cancer, especially rarer cancers like bladder cancer, occur during a short time period in a group of people or if cancers are seen in young people. The group of people may have something in common, like living in the same neighborhood or working in the same plant, over time.

Pollution and workplace exposures account for only about seven percent of cancers. Some common agents in the environment can cause cancer, like asbestos, ultraviolet rays from the sun, radon, and benzene in gasoline. If an individual is exposed to these agents, at work or at home, his/her risk of getting cancer depends on how much of the cancer-causing agent they came in contact with, and for how long.

DHEC's cancer cluster staff work closely with the South Carolina Central Cancer Registry to find out if the number of reported cases is greater than what would be expected for that size population or time period. Investigations of reported clusters are important, because they can help determine an excess of cancer in a community or examine cancer risks in the environment. Nationwide, cluster investigators find that about 90 percent of reports are not "true clusters".

There are an increasing number of reports of clusters among neighbors, friends, and co-workers for several reasons:

- People are living longer, and age is the number one risk factor for cancer.
- The word cancer is no longer taboo and individuals in our society are more likely to discuss this disease.
- Today survival rates for most cancers are much higher, therefore, we are more likely to know someone who has had cancer.

Savannah River Regional Health Information System

Dan Lackland, Dr PH, Medical University of SC

Another resource for South Carolinians who are concerned about the impact of the environment on their community is the Savannah River Regional Health Information System (SRRHIS). SRRHIS began as a joint project of the Medical

University of South Carolina and Emory University to develop and maintain a cancer registry incorporating counties within 50 miles of the Savannah River Site (SRS), and those downstream to Beaufort and Savannah. This region comprised 22 counties in all, 10 in South Carolina and 12 in Georgia.

In January of 1997, SRRHIS published its first report about the occurrence of cancer in the Savannah River region. This report was based on more than 13,000 cases of cancer identified as newly diagnosed among SRRHIS residents during the years 1991 through 1993. The program aims were to provide a precise measure of the incidence of cancer in the area; to track their frequency over time; to promote research on the causes of cancer and ways to prevent or detect them earlier; and to promote the dissemination of information to the residents and professionals of the geographic area.

SRRHIS Community Education

In 1996, the SCCCR took over data collection for the Savannah River region. The current priority of SRRHIS is to be a forum for health concerns of the area's residents. A particular emphasis includes cancer rates and risks for the citizens in the Savannah River Region.

The SRRHIS Steering Committee is made up of multi-disciplinary professionals and residents of the Savannah River Region who serve in an advisory capacity to the project director. The 12 committee members constitute a variety of backgrounds representing Georgia and South Carolina. The committee meets quarterly, rotating the meeting place among the cities in the Savannah River Region. These meetings are open to the public and notices announcing the time and location are placed in local newspapers.

In an effort to inform the regional residents that SRRHIS recognizes their concerns about possible adverse health effects from environmental hazards, a series of community information/education meetings were developed. Through these meetings, SRRHIS informs the community about its goals and methods. They also constitute a forum for bringing out and identifying resident suggestions and concerns.

Risk Perception

Kathleen Whitten, University of Virginia

People often have difficulty knowing what poses a risk to their health. There might be several reasons for this — they can't read well and so they don't understand complex, technical information, or they refuse to believe that pleasurable activities like sunbathing or eating barbecue could contribute to their risk of developing cancer. Studies have shown that people are willing to accept 1,000 times the risk of injury of illness from an activity they want to do, like swimming or skiing, than from something they can't control, like pollution or a nuclear accident, even if they think the benefits are the same. In general, people say they have more fear of risks that they can't control, that might be fatal, are involuntary and might affect future generations (Weiss and Lee, 1996).

People are less fearful about known risks they can control, such as tobacco and alcohol use, than about nerve gas accidents and nuclear war, even though the latter are far less likely to cause health problems because they are so very rare. But people's distorted perceptions of risk might affect the way they react to health messages about the risks of smoking, alcohol and high-fat diets in relation to cancer. Inaccurate risk perceptions may also lead people to make inappropriate decisions about changing their risky behaviors. Health professionals need to take psychological reactions to risk into account in designing educational campaigns that encourage risk reduction.